

**FEDERAL PATIENT CENTERED MEDICAL HOME (PCMH) COLLABORATIVE**  
Catalogue of Federal PCMH Activities *as of March 2011*

**OPERATING DIVISION/DEPARTMENT:**

National Cancer Institute (NCI) of the National Institutes of Health (NIH)

**Respondent:**

- Dr. Neeraj Arora, Research Scientist and Program Director for Patient-Centered Care Research in the Outcomes Research Branch of the Applied Research Program, Division of Cancer Control and Population Sciences

**PRÉCIS:**

NCI's work is focused on cancer but supports the core principles of the PCMH model of care, namely patient-centeredness, care coordination, and appropriate communications. NCI primarily funds research activities and has published a variety of reports and tools that are of use to the design and improvement of a medical home model.

**STRATEGIC GOALS OF THE OPERATING DIVISION/DEPARTMENT:**

- *Research initiatives support advancing the patient-centered medical home.* In 2006, NCI started a patient-centered cancer care research initiative. Although NCI does not explicitly support the medical home model, patient centeredness is a significant priority for the division of cancer control and population sciences.

The research initiative seeks to advance conceptualization, measurement, monitoring, and improvement of patient-centered cancer care, and in particular, will use patient experience measures of quality of care to complement technical measures. NCI wants to include experience measures in construction of the electronic health record as a way to improve the delivery of patient-centered care. NCI is currently thinking of ways to incorporate the PCMH in oncology from the perspective of coordinating care across specialties.

**AREAS OF PCMH ACTIVITY:**

**Research (includes evaluation)**

- *Monograph on Patient-Centered Communication in Cancer Care.* In 2007, NCI published a monograph on patient-centered communication in cancer care under contract with researchers from the University of Rochester and Texas A&M University. The monograph outlines a six-function framework that patient-centered health systems should support. The six core functions outlined are: 1) fostering healing relationships, 2) exchanging information, 3) responding to emotions, 4) managing uncertainty, 5) making decisions, and 6) enabling patient self-management. This monograph has been widely disseminated and has informed a lot of the research on patient-clinician communication of NCI grantees.

- *DEcIDE Network research on patient-centered communication.* Following the 6-function framework described above, NCI provided funding to AHRQ for a DEcIDE (Developing Evidence to Inform Decisions about Effectiveness) Network project that funded RTI International to identify the measurable domains and subdomains for each of the 6 functions of patient-centered communication. The project team interviewed patients, clinicians, and family members; updated a literature review; brought experts to the table; and triangulated 3 different data inputs in order to create a list of domains that could be measured to assess comprehensively the delivery of patient-centered communication. A manuscript describing findings is available at <http://www.ncbi.nlm.nih.gov/pubmed/21376443>. A follow-on project was also awarded to RTI to create an item bank of measures for each of the domains identified in the first project. This effort resulted in a comprehensive item bank of more than 150 items assessing the different functions of patient-centered communication. These items underwent extensive cognitive testing and will be available for public dissemination in 2011. It is hoped that these items will facilitate the development of more valid measures of patient-centered communication.
- *Methods for Longitudinal Assessment of Patient-centered Care (MAPCare).* NCI supports the Centers of Excellence in Cancer Communication Research (CECCR) program to facilitate cutting edge research in health communication. See <http://www.cancercontrol.cancer.gov/hcirb/ceccr/ceccr-index.html> for more information about the grant program. NCI recently provided supplement grant funding to the Cancer Research Network's (<http://crn.cancer.gov/>) Cancer Communication Research Center, one of the CECCR grantees, to develop a blue print for an electronic system to collect uniform, longitudinal data on patient-centered cancer communication in all 14 HMOs that participate in the CRN. The project involves detailed interviews with patients, family members, clinicians, health administrators, and IT directors to understand their perspective on the ideal set of measures, data collection frequency and modality, and system requirements that would enable the measurement, monitoring, and improvement of the patient-centeredness of patient-clinician communication in cancer care.

## Other

- *Cancer CAHPS tool.* With funding from AHRQ and NCI awarded to the American Institutes for Research (AIR) and the Mayo Clinic as part of AHRQ's ACTION Network projects, NCI and AHRQ are collaborating to create a cancer version of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey. The Cancer CAHPS survey aims to comprehensively assess cancer patient experiences of receiving treatment in a variety of health care delivery settings. Given the complexity of patient-clinician interactions in oncology compared to primary care settings, the Cancer CAHPS instrument builds upon existing CAHPS instruments to capture in more detail topics such as information exchange, care coordination, shared decision-making, symptoms and side effects management, and patient safety. The contractors have developed a draft of an instrument based on literature synthesis, focus groups, and expert input. In 2011,

this instrument will undergo cognitive testing and refinement, followed by a large scale pilot test to assess the psychometric properties of the measures.

## **MATERIALS:**

### **Reports and Monographs**

- *Patient Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*. The citation for the monograph described above is: Epstein RM, Street RL Jr. Patient Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. National Cancer Institute, NIH Publication No. 07-6225. Bethesda, MD, 2007, and is available from <http://outcomes.cancer.gov/areas/pcc/communication/monograph.html>.
- *Toward Improving the Quality of Cancer Care: Addressing the Interfaces of Primary and Oncology-Related Subspecialty Care*. This monograph looks at issues of quality cancer care across the cancer care continuum. It specifically examines care transfer and associated breakdowns during such transitions. The monograph is: S Taplin and A Rogers (eds). *Toward Improving the Quality of Cancer Care: Addressing the Interfaces of Primary and Oncology-Related Subspecialty Care*, *Journal of the National Cancer Institute Monographs* (2010) 2010(40): 3-10, and is available from <http://jncimono.oxfordjournals.org/content/2010/40/3.extract>.

### **ACTIVE PCMH COLLABORATIONS WITH FEDERAL PARTNERS:**

NCI convenes the Quality of Cancer Care Committee (QC3), a trans-federal committee focused on improving the quality of cancer care. Currently, the QC3 is planning a collaborative effort, based on PCMH principles, to improve care coordination within the context of cancer care. Demonstration projects on improving care coordination are being planned with the Veterans Administration (VA) and the Indian Health Service (IHS). Active members of the QC3 include AHRQ, CMS, CDC, VA, IHS, HRSA, and NIH.